TESTIMONY OF MR. CARL HICKS

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BEFORE THE HOUSE ENERGY AND COMMERCE
SUBCOMMITTEE ON HEALTH

"IMPROVING AMERICA'S HEALTH: EXAMINING FEDERAL RESEARCH EFFORTS FOR PULMONARY HYPERTENSION AND CHRONIC PAIN."

THURSDAY, DECEMBER 8, 2005 10:00AM

<u>SUMMARY OF TESTIMONY:</u>

1) INTRODUCTION TO PULMONARY HYPERTENSION AND THE PULMONARY HYPERTENSION ASSOCIATION.

2) PERSONAL STORY OF MEAGHAN HICKS' BATTLE WITH THE DISEASE.

3) DISCUSSION OF H.R. 3005, THE "PULMONARY HYPERTENSION RESEARCH ACT."

Mr. Chairman, Congressman Brown and distinguished members of the subcommittee, thank you for convening this important hearing this morning and for the opportunity to testify. I am Carl Hicks, Vice President for Advocacy with the Pulmonary Hypertension Association, and a proud parent of a pulmonary hypertension patient.

I am honored today to represent the hundreds of thousands of Americans who are fighting a courageous battle against this devastating disease. In particular Mr. Chairman, I am pleased to bring greetings to you from the PHA Georgia Youth Group, which is headquartered in your congressional district, in Loganville. This is one of PHA's outstanding support groups for young PH patients, led by a terrific volunteer named Robin Chambless.

Pulmonary hypertension is a serious and often fatal condition where the blood pressure in the lungs rises to dangerously high levels**.** In PH patients, the walls of the arteries that take blood from the right side of the heart to the lungs thicken and constrict. As a result, the right side of the heart has to pump harder to move blood into the lungs, causing it to enlarge and ultimately fail.

PH can occur without a known cause or be secondary to other conditions such as; collagen vascular diseases (i.e., scleroderma and lupus), blood clots, HIV, sickle cell, and liver disease. PH does not discriminate based on race, gender or age. Patients develop symptoms that include shortness of breath, fatigue, chest pain, dizziness, and fainting. Unfortunately, these symptoms are frequently misdiagnosed, leaving patients with the

false impression that they have a minor pulmonary or cardiovascular condition. By the time many patients receive an accurate diagnosis, the disease has progress to a late stage, making it impossible to receive a necessary heart or lung transplant.

While new treatments are available, unfortunately, PH is frequently misdiagnosed and often progresses to late stages by the time it is detected. Although PH is chronic and incurable with a poor survival rate, the new treatments becoming available are providing a significantly improved quality of life for patients. Recent data indicates that the length of survival is continuing to improve, with some patients able to manage the disorder for 20 years or longer.

Fifteen years ago, when three patients who were searching to end their own isolation founded the Pulmonary Hypertension Association, there were less than 200 diagnosed cases of this disease. It was virtually unknown among the general population and not well known in the medical community. They soon realized that this was unacceptable, and formally established PHA, which is headquartered in Silver Spring, Maryland.

Today, PHA includes:

- Over 6,000 patients, family members, and medical professionals.
- An international network of over 120 support groups.
- An active and growing patient telephone helpline.

- A new and fast-growing research fund. (A cooperative agreement has been signed with the National Heart, Lung, and Blood Institute to jointly create and fund five, five-year, mentored clinical research grants and PHA has awarded eleven Young Researcher Grants.)
- A host of numerous electronic and print publications, including the first medical journal devoted to pulmonary hypertension – published quarterly and distributed to all cardiologists, pulmonologists and rheumatologists in the U.S.

Mr. Chairman, I want to take this opportunity to express PHA's deep gratitude to Congressman Kevin Brady and Congressman Tom Lantos for their leadership on our behalf. As you know, they have introduced H.R. 3005, the "Pulmonary Hypertension Research Act" in the House of Representatives. This landmark bill for our community has 241 bipartisan co-sponsors, 17 of whom are members of this subcommittee. We owe a lot to these great champions, and we are particularly grateful for Congressman Lantos's beautiful and courageous granddaughter Charity, who is with us today. Charity's spirit, determination and dedication to the fight against this disease inspires us each and every day.

I want to tell you the story of another beautiful and courageous young woman, my daughter Meaghan. The impact of this disease upon so many Americans and their family members is comparable to a nightmare you can never wake up from, right from the start. For my family, it began with the words spoken not far from here at Walter Reed Army Medical Center a few years back. "Colonel Hicks," the doctor said, "your daughter

Meaghan has less than a year to live. We can do nothing for her." Since that time she has fought a valiant and protracted fight, and due to the hellishness of this disease, we have very nearly lost her 3 times, twice in the past two months. To remain alive now, she must take over 12 different pills daily, as well as flolan, an IV drug delivered by pump directly to her heart through her chest wall 24 hours a day. She'll never know the joy of motherhood or even marriage. Were she to marry she would lose my insurance benefits that are keeping her alive.

Mr. Chairman, you may be astounded to know that we have more Americans dying today from this illness, that is widely believed to ultimately be curable, than were tragically lost in combat in all conflicts that we have encountered since the final year of WWII. Yes, that includes Vietnam, Korea and all the rest, dying today, in the U.S. of this illness. Even with a scope that horrific, I am sometimes asked why we should pay attention or focus resources on that terminal illness instead of others, of which there are many. The answer is, quite simply, because we can.

Mr. Chairman, hope for our patients and their families lies in advancements made through biomedical research. According to leading scientists in the field, we are on the verge of tremendous breakthroughs in both our understanding of the disease and the development of new and advanced treatments. Our scientists are more hopeful than they have ever been regarding the future of research in PH. Ten years ago, a diagnosis of PH was essentially a death sentence, with only one approved treatment for the disease.

Thanks to advancements made through both the public and private sector, patients today are living longer and better lives with a choice of five FDA approved therapies.

On behalf of PHA, I would like to take this opportunity to thank NHLBI Director Dr. Betsy Nabel and her colleagues for their leadership in the battle against this disease. We are very proud of our partnership with the Institute and we are grateful that Dr. Gladwin has taken the time to share his knowledge and insight with us at the hearing today.

Recognizing that we have made tremendous progress, we are also mindful that we are a long way from where we want to be, and that is a) the management of pulmonary hypertension as a treatable chronic disease and b) a cure for this devastating condition. That is why the "Pulmonary Hypertension Research Act" is so important to our community.

H.R. 3005 calls for the establishment of three Centers of Excellence on Pulmonary Hypertension through the National Heart, Lung and Blood Institute at the National Institutes of Health.

<u>These Centers would focus on the following activities</u> …

a) Basic and clinical research into the cause, diagnosis, early detection, prevention, and treatment of pulmonary hypertension..

b) Training programs designed to develop the next generation of pulmonary hypertension investigators..

c) Continuing education on pulmonary hypertension for health care professionals to help facilitate more accurate and timely diagnosis.

d) Dissemination of information to the public on pulmonary hypertension to raise awareness of the disease.

In addition, the legislation calls on the National Heart, Lung and Blood Institute to establish a pulmonary hypertension data system and clearinghouse.

Mr. Chairman, all of these activities are essential to our efforts to take the next step in the fight against this disease. However, you don't have to rely solely on our word regarding the need for additional research. On November 11th the Centers for Disease Control and Prevention released a long awaited Morbidity and Mortality Report on pulmonary hypertension. In that report, the CDC states;

1) " More research is needed concerning the cause, prevention, and treatment of pulmonary hypertension. Public health initiatives should include increasing physician awareness that early detection is needed to initiate prompt, effective disease management. Additional epidemiologic initiatives also are needed to ascertain prevalence and incidence of various pulmonary hypertension disease entities." *(Page 1, MMWR Surveillance Summary – Vol. 54 No. SS-5)*

2) "Prevention efforts, including broad based public health efforts to increase awareness of pulmonary hypertension and to foster appropriate diagnostic evaluation and timely treatment from health care providers, should be considered. The science base for the etiology, pathogenesis, and complications of pulmonary hypertension disease entities must be further investigated to improve prevention, treatment, and case management. Additional epidemiologic activities also are needed to ascertain the prevalence and incidence of various disease entities." *(Page 7, MMWR Surveillance Summary – Vol. 54 No. SS-5)*

Moving forward, PHA would like to work with Congress and the NHBLI to facilitate the establishment of the Centers of Excellence on Pulmonary Hypertension called for in the "PH Research Act." The overwhelming support for this bipartisan legislation speaks to the strong interest of members on this issue, and we hope to make real progress in establishing these Centers in 2006. Working together, I am confident that we can find a cure for Meaghan, Charity and the hundreds of thousands of other patients pinning their hopes for a better life on biomedical research.

Mr. Chairman, thank you again for the opportunity to appear before you today. We appreciate your interest and your leadership on these issues. I would be pleased to respond to any questions you may have.